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Huntington Disease Genetic Test Taking: A Challenge between Modern Medical Technology and Humanity

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Opinion

Many previous studies investigated the ethical issues and psychological effect behind on the disclosure of Huntington Disease (HD) [1]. Huntington Disease is a devastating and degenerative brain disorder, where it slowly diminishes the affected individual's ability to physical movements, cognitive, and behavior disturbance [2]. The cognitive dysfunctions may include disorganized thoughts, planning, searching for alternatives, and delays the acquisition of new motor skills [1]. HD affects the physical movements by the inability to maintain a constant voluntary muscle contraction at a constant level [1]. HD can occur to people ages from 2 to 80 but symptoms typically strike at midlife [3]. The disease is characterized by chorea, a progressive dementia [4]. The disease can eventually lead to death, which normally occurs ten to seventeen years after initial onset [5].

Huntington's disease is the most common inherited neurological disorder, with prevalence ranging from 4.1 to 7.5 cases per 100,000 in Caucasians average 5.6 cases per 100,000 Caucasians, however, with wide variation [6]. Prevalence is less common in Asia and Africa, where approximately 1 in a million are born with the gene [7]. HD is a genetic disorder that develops in people who have inherited a larger than normal *huntington* gene on chromosome 4 [1]; the expansion in the gene is due to the repetition of CAG [7]. The larger *huntington* gene produces an abnormal protein that initiates death of brain cell in the middle age [8].

It has no confirmative pharmacological therapy for HD; therefore other means of management therapies may be used such as cooperating with patient's families and health care professionals, and managing behavior anomalies [2]. Eventually, the patients become dependent upon others for their care; thus, HD profoundly affects the lives of entire families emotionally, socially, and economically causing extreme burden [9,10]. Reported that families of a Huntington Disease patients go through different stages such as adjusting the impact, searching for information that helps them cope with the situation, gathering support from different sources, bolstering spirit, designing individual care, and facing the uncertainty in the future.

Genetic testing has been available for patients to predict the HD and is almost 100% acute by detecting the gene. There is a high inheritance rate of HD of 50% chance as the disease acquires an autosomal dominant pattern if parents were positive with HD [11]. A positive result of the genetic testing signifies that they will develop HD [10]. Genetic information solves the uncertainty of illness, reveals correct information, and consequently sometimes diminishes people's anxiety and fear of the unknown. However, this new knowledge of genetic information maintains openly to be investigated of ethical issues of informed consent, shared decision-making and types of truth telling. Uncovering the participants' voices and lived experiences and the professional's own potential values and actions through various socio-cultures and medical-institutions or communities may provide deeper understanding the relationship and meaning between the modern medical technology and humanity.

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